

LEGALISED PHYSICIAN-ASSISTED DEATH IN OREGON

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In the United States, five states have legalised physician-assisted death ('PAD'), but most information and research comes from the state of Oregon, in which the practice has been legal since 1997. This law allows a physician to prescribe a lethal dosage of medicine to terminally ill, mentally competent residents, for the purposes of self-administration. About 3 in 1000 deaths are now from PAD and the patients most often have cancer or amyotrophic lateral sclerosis. Concerns that legalisation would undermine the development of palliative care and be disproportionately utilised by patients unable to access good end of life care have been unfounded.

I INTRODUCTION

As of 2016, five US states have legalised physician-assisted death ('PAD'), through a variety of pathways. In the Northwest states of Oregon and Washington, PAD was legalised through citizens' initiatives, as both states have methods in which constituents can petition to have laws changed by statewide vote. The *Oregon Death with Dignity Act* was passed 20 years ago in 1994, though legal challenges delayed enactment until 1997. In 2008, voters in neighbouring Washington passed an almost identical law.¹ More recently a judge in Montana ruled that physicians cannot be prosecuted for prescribing lethal medications for terminally ill, mentally competent patients.² In 2013 and 2015, the legislatures of the state of Vermont and California respectively legalised PAD. The laws in Oregon, Washington, California and Vermont include safeguards that limit the conditions under which lethal prescriptions can be written and methods for publishing statistical data on the use of lethal prescriptions (little information is available from Vermont at this time). In contrast, there is almost no information about PAD from Montana as the pathway through which legalisation occurred did not result in any reporting requirements and, to date, no independent researchers have published any information. No other form of PAD — that is, physician prescription and patient consumption of medications for the sole purpose of causing death — is legal in the US at this time. The focus of this paper is on available information from Oregon, in which many years of published data from the state and independent research have resulted in substantial information on the practice of PAD.

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¹ Elizabeth Trice Loggers et al, 'Implementing a Death with Dignity Program at a Comprehensive Cancer Center' (2013) 368(15) *New England Journal of Medicine* 1417.

² *Morris v Brandenburg*, No D-202-CV 2012-02909 (NM 2d Jud Dist Jan 13, 2014); *Baxter v Montana*, 2009 MT 449 (Mont, 2009).

A survey in 1995 reported that before legalisation 7 per cent of Oregon physicians had ever prescribed medications to be used to cause death.³ Back and co-authors surveyed 828 Washington physicians in 1996.⁴ Ninety-nine (12 per cent) of physicians had received a request for physician assisted death in the previous year and 32 had complied. A national survey from 1998 reported that 3.3 per cent of US physicians had ever written a prescription to hasten death.⁵ This data suggests that a significant minority of physicians in Oregon and Washington were willing to participate in aid in dying even before legalisation and that physician-assisted death does occur outside the law across the US.

II LEGALISED PHYSICIAN-ASSISTED DEATH IN OREGON AND WASHINGTON

The Oregon and Washington *Death with Dignity Acts* are nearly identical.⁶ They allow a competent adult resident of the state to obtain a prescription from a physician for a lethal dose of medication, for the purposes of causing death through self-administration. The laws do not allow lethal injection nor can individuals acquire a lethal prescription through advance directive to be used when mentally incapable in the future. A variety of safeguards limit the conditions under which the prescription can be written. Two physicians, one of whom will write the prescription, must confirm that the patient has a terminal illness (likely to cause death within six months), is competent to make the decision, and is doing so voluntarily. Individuals must be informed of the options of hospice and comfort care. In order to minimise the risk of impulsive decisions, individuals must make one written request and two oral requests over a period of 15 days. The patient must be referred to a psychiatrist or a psychologist if there is concern that the request for a lethal prescription stems from impaired judgment resulting from mental illness such as depression. The physician must request, though may not require, that the patient inform their family of the request. Physicians who do not comply with the laws' requirements may be subject to action from the state licensing board. Several Oregon physicians have been investigated, though for relatively minor problems in documentation.

Prescribing physicians are required to report information to the state on patients who receive prescriptions; they are not required to report any information on requests that do not result in a prescription; therefore, less is known about the reasons why patients are denied prescriptions. Annual statistical reports include the number of prescriptions written, characteristics of patients who have died of PAD, and complications. These reports are comprehensive in including every individual who received a prescription under the law, and allow tracking of changes in practice over time. They contain no information on PAD, including euthanasia that occurs outside the law. Other information about PAD comes from groups of researchers in each state who have used a variety of methods including surveys, interviews and qualitative studies to examine the

³ Melinda A Lee et al, 'Legalizing Assisted Suicide: Views of Physicians in Oregon' (1996) 334(5) *New England Journal of Medicine* 310.

⁴ Anthony L Back et al, 'Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses' (1996) 275 *Journal of the American Medical Association* 919.

⁵ Dianne E Meier et al, 'A National Survey Of Physician-Assisted Suicide and Euthanasia in The United States' (1998) 338 *New England Journal of Medicine* 1193.

⁶ Oregon Public Health Division, *Oregon's Death with Dignity Act – 2014* <<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>>; Washington State Department of Health, *Washington State Department of Health 2014 Death with Dignity Act Report* (2014) <<http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct>>.

practical aspects of the law; its impact on end of life care; and the views and experiences of health care professionals, requesting patients, and their families.

Oregon, with statistical reports from the state extending back to 1999, has the most comprehensive data on legalised PAD, though initial data from Washington is similar on most measures. Up to the end of 2014, under Oregon's law, 859 Oregonians have died by PAD. The rates have increased slowly from 1 in 1000 deaths to, in 2014, 3 in 1000 deaths (an average of 2 in 1000 deaths during the law's operation). Opponents of the law believe this increase is evidence of the anticipated slippery slope, whereas supporters of the law underscore the very low rate overall, even with the slow increase over time. The median age of decedents is 71 years, almost equally divided between men and women. Racially 97 per cent were white, 1 per cent were Asian and 0.7 per cent were Hispanic. The most common terminal diseases were cancer (78 per cent) and amyotrophic lateral sclerosis (8 per cent). Overall, 90 per cent had been enrolled in hospice, 95 per cent died at home, and 1.5 per cent lacked medical insurance. Ninety-three per cent of individuals informed their family of the decision. After taking the medications, most commonly secobarbital or pentobarbital, patients became unconscious on average within five minutes and died within a median of 25 minutes. Complications included regurgitation in 22 patients and regaining of consciousness after ingestion of medication in six patients.⁷ The Oregon Department of Human Services compared those who died by PAD to all other Oregon decedents through 2005: those who die by PAD are less likely to be very old, less likely to be married, and more likely to have cancer.⁸ In addition PAD deaths occur in persons with much higher levels of education — PAD decedents are 8 times more likely to have completed college education. In Oregon the risk of choosing PAD is comparatively very high in patients with ALS (rate ratio 31, 95 per cent confidence interval 14.4-73.5) and HIV (rate ratio 25.1, 95 per cent confidence interval 6.9-80.4), though the absolute numbers of PAD deaths from these diseases are small because these diseases are relatively rare compared to other causes of death.⁹ In 2014, 83 physicians wrote the 155 prescriptions provided.

III PHYSICIAN-ASSISTED DEATH, PALLIATIVE CARE AND HOSPICE

Throughout the United States, individuals become eligible for hospice care at the time they have less than six months expected life and are no longer pursuing life-sustaining treatment. Financially, hospice organisations are paid on a per diem rate, not, as in much of the rest of US medicine, a fee-for-service payment. Within that financial structure, most hospice services are delivered at the patient's home, with visits from hospice nurses, social workers, and other personnel depending on the patient's needs. Oregon has around 60 different hospice organisations, though most offer a similar set of federally mandated services. Even the most rural and sparsely populated areas of Oregon have hospice coverage. Palliative care services, for patients not enrolled in hospice, are delivered in the hospital or in outpatient settings and are mostly supported through medical centers because insurance payments often do not adequately

⁷ Oregon Public Health Division, *Oregon's Death with Dignity Act – 2014* <<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>>.

⁸ Oregon Department of Human Services, Office of Disease Prevention and Epidemiology, *Eighth Annual Report on Oregon's Death with Dignity Act* (9 March 2006) <<http://euthanasia.procon.org/sourcefiles/EighthAnnual.pdf>>.

⁹ Ibid.

cover the costs. At the time of passage of Oregon's *Death with Dignity Act*, there was concern that legalised PAD might undermine support for hospice and palliative care, both of which were early in their development. The costs of expanding and improving the quality of hospice and palliative care against the minimal costs of a lethal prescription provoked fears of subtle pressure for PAD.¹⁰ In fact, PAD became an option within hospice, with 90 per cent of PAD decedents hospice enrolled. Advocates for palliative care were able to effectively use the specter of bad publicity around patients choosing PAD because of denial of care with hospital administrators, insurers and the state. Hospitals added palliative care services and most insurers, including Medicaid, the primary health care insurer for the poor, covered hospice. During the three years of preparation allowed between passage of the law in 1994 and implementation in 1997, Oregon health care leaders came together to develop educational programs and both advocates and opponents of PAD legalisation agreed on the importance of good palliative care. Uptake of interest in hospice and palliative care among Oregon's health care providers was strong. In a survey of over 2600 Oregon physicians soon after the law's enactment, 30 per cent agreed they made higher rates of hospice referrals the previous year compared to five years earlier; only 2 per cent of surveyed physician indicated they had made fewer referrals. Among the over 2000 who had cared for at least one terminally ill patient in the previous year, 76 per cent reported they had made efforts to improve their knowledge of the use of pain medications 'somewhat' or a 'great deal'.¹¹ Hospice professionals agreed. In a 2001 survey of 237 hospice nurses and social workers, 67 per cent ranked Oregon physicians as more competent in caring for hospice patients than five years earlier, and 4 per cent viewed them as less competent; 77 per cent viewed them as more willing to refer to hospice compared to five years earlier, and only 3 per cent viewed them as less willing.¹² These improvements paralleled increases across the US in palliative care and hospice services, and cannot necessarily be credited to legalisation of PAD. Yet the concern that PAD would undermine end of life care was not supported.

PAD was ultimately rarely chosen by terminally ill patients, with, over the period of the law's operation through to 2014, only 2/1000 deaths in Oregon attributed to this. Only one in ten who make explicit requests die by lethal prescription.¹³ In part this may reflect barriers to obtaining the prescription—patients require planning and foresight as many physicians are unwilling to participate in prescribing. Only one third of Oregon physicians are willing to prescribe.¹⁴ Although there is a 15-day waiting period from time of initial request to obtaining the prescription, in fact the median time between first request and death is 47 days. Some patients lose the ability to participate because they succumb to their disease before they complete the process, or develop physical symptoms that make it difficult to ingest the medication. Physicians are very reluctant to prescribe to patients if there are family members with objections.¹⁵

¹⁰ Elizabeth R Goy et al, 'Oregon Hospice Nurses And Social Workers' Assessment Of Physician Progress In Palliative Care Over The Past Five Years' (2003) 1 *Palliative and Supportive Care* 215.

¹¹ Linda Ganzini et al, 'Oregon Physicians' Attitudes About And Experiences With End-Of-Life Care Since Passage Of The Oregon Death With Dignity Act' (2001) 285 *Journal of the American Medical Association* 2363.

¹² Goy et al, above n 10.

¹³ Linda Ganzini et al, 'Physicians' Experiences with the Oregon Death with Dignity Act' (2000) 342 *New England Journal of Medicine* 557.

¹⁴ *Ibid.*

¹⁵ Linda Ganzini et al, 'Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families' (2003) 6 *Journal of Palliative Medicine* 381.

Palliative interventions, particularly referrals to hospice, did result in some patients changing their mind about pursuing PAD.¹⁶

Another challenge to care providers at the end of life is that individuals who request PAD often are motivated by concerns that are not easily ameliorated by hospice care. Although many of the arguments around legalisation focused on pain, a surprising finding is that most patients at the time of their first request for PAD have minimal pain — though fear of future pain is a more important reason for requests.¹⁷ Because most patients receive the prescription before they actually experience substantial pain, there is less of a role for expert pain management in reducing prescriptions. The reasons individuals give for wanting access to PAD are primarily to maintain independence and control, minimise dependence on others, and die at home. Furthermore the desire for independence and control represent lifelong values and characteristics, not transient, illness-based perspectives.¹⁸ For hospices, PAD patients can present a variety of challenges both for individual practitioners and at a policy level. For individual practitioners, those opposed to PAD may believe they have failed when their patients choose to take the lethal medication.¹⁹ Many believe that a natural death offers opportunity for growth and spiritual transformation for both the patient and family that is missed when the patient chooses PAD. Hospice nurses with discomfort around PAD struggle to maintain boundaries and not be drawn in, for example, being asked to manage a symptom such as nausea to help prepare a patient to take the medication.²⁰ But overall, in surveys completed in Oregon within five years of legalisation, 48 per cent of hospice nurses, 72 per cent of hospice social workers, and even 40 per cent of hospice chaplains supported the law, and very few hospice workers would decline to care for such a patient.²¹ It is possible for patients to obtain prescriptions and take them without ever telling their hospice provider as the prescribing physician-patient relationship may be entirely separate from the hospice.

Among the hospice organisations in Oregon, policies around PAD vary. All hospices share core values of not hastening death, not abandoning patients, and respecting both the patient-physician and the interdisciplinary team relationships but they differ in how they balance these values. Campbell and Cox outline a variety of organisational positions and policies of Oregon hospices around PAD.²² Oregon hospices will not discharge a patient who entertains the goal of PAD, yet no hospice will provide the patients with the lethal medication or assist in the self-

¹⁶ Linda Ganzini and Steven K Dobscha, 'Clarifying Distinctions Between Contemplating And Completing Physician-Assisted Suicide' (2004) 15 *Journal of Clinical Ethics* 119.

¹⁷ Linda Ganzini, Elizabeth R Goy and Steven K Dobscha, 'Oregonians' Reasons for Requesting Physician Aid In Dying' (2009) 169 *Archives of Internal Medicine* 489.

¹⁸ Ibid.

¹⁹ Theresa A Harvath et al, 'Dilemmas Encountered by Hospice Workers When Patients Wish to Hasten Death' (2006) 8 *Journal of Hospice and Palliative Nursing* 200.

²⁰ Ibid.

²¹ Linda Ganzini et al, 'Experiences Of Oregon Nurses And Social Workers With Hospice Patients Who Requested Assistance With Suicide' (2002) 347 *New England Journal of Medicine* 582; Bryant Carlson et al, 'Oregon Hospice Chaplains' Experiences With Patients Requesting Physician-Assisted Suicide' (2005) 8 *Journal of Palliative Medicine* 1160.

²² Courtney S Campbell and Jessica C Cox, 'Hospice And Physician-Assisted Death: Collaboration, Compliance, And Complicity' (2010) 40 *Hastings Center Report* 26; Courtney S Campbell and Jessica C Cox, 'Hospice-assisted Death? A Study of Oregon Hospices on Death with Dignity' (2012) 29 *American Journal of Hospice Palliative Care* 227.

administration. Within these boundaries, hospices vary on the degree to which they allow staff to discuss PAD with the patient, notify the attending physician of the patient's interest in PAD, refer the patient to an advocacy organisation for more information, or allow hospice staff presence before or during ingestion of the medication. For example, hospices range from the minority of mostly religiously-based hospices that view PAD as incompatible with hospice care, will not provide information about patient choices, and ask patients to respect their hospice's position to those that emphasise respect for patient self-determination, allow hospice personal to openly discuss this option, refer the patient to PAD advocacy organisations for more information, or attend the death by PAD.

IV OTHER CONCERNS REGARDING OREGON'S LAW

The laws in Washington and Oregon have been criticised as both inadequate in safeguards and lacking in enforcement in safeguards. For example, unlike the Netherlands, intolerable suffering is not a requirement for legal euthanasia, reflecting the primary role of autonomy and self-determination in support for the law. Neither state requires that the primary or the consulting physician have expertise in palliative care. Patients are evaluated to make sure they have decision making capacity when they receive the prescription, but there are no safeguards to assure they are of sound mind at the time they take the prescription. Although patients become eligible under the law at the time they have less than six months life expectancy, some patients who obtain prescriptions outlive this life estimate, bringing into question the accuracy of physician assessment of prognosis. In 2015 the Oregon legislature is considering a bill to expand eligibility to persons who have a one year life expectancy. This change is opposed by Compassion and Choices, the chief advocacy organisation for persons choosing PAD, as it would leave some patients potentially choosing PAD who were not yet eligible for hospice benefits.²³ Because many physicians decline to participate in the law or work for religious health care systems that contractually preclude them from participating, patients who wish to secure lethal prescriptions often must find a new physician late in the course of their terminal illness if they wish to access a lethal prescription. There are concerns that the physician may not know the patient well enough to prescribe in such cases.

Safeguards are written into the law to make sure that patients are competent and not requesting PAD because of a treatable mental illness. Although mental illness itself does not exclude patients from obtaining lethal prescriptions, the assessment that mental illness impacts the patient's judgment to hasten death does require evaluation by a psychiatrist or psychologist. As stated in the law 'No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment'.²⁴

Although 'depression' is not defined in the law, this is accepted to refer to 'clinical depression' or, in psychiatric nomenclature, major depressive disorder. During an episode of major depressive disorder a patient has pervasive low mood; inability to experience pleasure; and has sad, blue or depressed feelings most of the time over weeks, so persistently that everyday functioning is impacted. Other symptoms include hopelessness, a belief of burdening others,

²³ Barbara Coombs Lee, 'Don't Change Eligibility for Death with Dignity Law' *Oregonian* (Oregon), 4 April 2015.

²⁴ Oregon Public Health Division, above n 7.

guilt, poor self-esteem, and desire to die. This type of depression differs from understandable and normal grief, sadness, and dysphoria experienced by many with a terminal illness. Major depressive disorder can be reliably diagnosed in between 10 per cent and 25 per cent of patients with advanced cancer.²⁵ Among persons requesting PAD in Oregon, we found that three quarters are confidently diagnosed as not depressed.²⁶

There are several important arguments for excluding patients with clinical depression from being eligible for PAD. Depressed persons view their future through a lens of pessimism and hopelessness. Major depressive disorder can render a person unable to enjoy life or experience pleasure, personal worth, or hope for recovery. Depressed persons therefore can make decisions that are inconsistent with their values, life philosophy, or personality, even if the decisions otherwise appear competent and voluntary. In fact, depression may not prevent expression of an articulate and coherent analysis of the benefits and rationale for PAD.²⁷ Depression and hopelessness are strongly associated with suicide in other contexts but suicidal patients may reembrace life with successful mental health treatment. Treatment of depression effectively reduces hopelessness and suicidal thoughts and ideation among older primary care patients.²⁸

There are also arguments for, in some cases, allowing patients with depression to access lethal prescriptions. Depression causes suffering at the end of life. Many patients who request PAD have only weeks of remaining life, yet most antidepressant treatment regimens are not effective until after one or two months of treatment. Successful treatment of major depressive disorder increases interest in life-sustaining treatments in only a minority of patients and only those with the most severe mood symptoms.²⁹ Understanding whether depression influences the decision for PAD requires knowing an individual over time while both depressed and euthymic. In a survey of Oregon psychiatrists, 95 per cent were ‘somewhat’ or ‘very confident’ in the context of a long-term relationship that they could determine whether a mental disorder, such as depression, was influencing the decision for PAD, but only 6 per cent were very confident that they could make this assessment in a single evaluation.³⁰ Ethical views on PAD may influence these assessments. In a national study of US forensic psychiatrists, those ethically opposed to PAD advocated for higher thresholds for competence — including that the finding of depression should result in automatic finding of incompetence and more extensive reviews of the decision, for example, more than one forensic examiner or judicial review.³¹ As such, the determination of whether depression is influencing the decision about PAD may reflect more about the mental health professional’s ethical and moral views of PAD than psychiatric expertise. In the US

²⁵ M Hotopf et al, ‘Depression in Advanced Disease: A Systematic Review Part 1. Prevalence and Case Finding’ (2002) 16 *Palliative Medicine* 81.

²⁶ Linda Ganzini, Elizabeth R Goy and Steven K Dobscha, ‘Prevalence of Depression and Anxiety in Patients Requesting Physicians’ Aid in Dying: Cross Sectional Survey’ (2008) 337 *British Medical Journal* 1682.

²⁷ Linda Ganzini and Steven K Dobscha, ‘If It Isn’t Depression’ (2003) 6 *Journal of Palliative Medicine* 927.

²⁸ Martha L Bruce et al, ‘Reducing Suicidal Ideation and Depressive Symptoms in Depressed Older Primary Care Patients: A Randomized Controlled Trial.’ (2004) 291 *Journal of the American Medical Association* 1081.

²⁹ Linda Ganzini et al, ‘The Effect of Depression Treatment on Elderly Patients’ Preferences For Life-Sustaining Medical Therapy’ (1994) 151 *American Journal of Psychiatry* 1631.

³⁰ Linda Ganzini et al, ‘Attitudes Of Oregon Psychiatrists Toward Physician-Assisted Suicide’ (1996) 153 *American Journal of Psychiatry* 1469.

³¹ Linda Ganzini et al, ‘Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists’ (2000) 157 *American Journal of Psychiatry* 595.

survey of forensic psychiatrists, 42 per cent did not agree that major depressive disorder should automatically exclude a patient from choosing assisted suicide.³²

The prevalence of depression in individuals in Oregon who actually request PAD does not appear to be markedly higher than the prevalence of depression in terminally ill patients who have not made such requests. In a study of Oregonians who requested PAD and underwent rigorous assessment for depression, 26 per cent met criteria for major depressive disorder.³³ Studies of the prevalence of depression in patients with terminal illness who are not seeking PAD report proportions of 10 per cent to 25 per cent.³⁴ Hospice social workers and nurses rated depression as a relatively unimportant reason that Oregon hospice patients requested PAD. In fact, among 21 reasons, hospice social workers, who have substantial experience in evaluating the psychosocial state of patients at the end of life, rated depression as mostly unimportant.³⁵

Though overall the burden of depression may be lower than anticipated among patients pursuing PAD, some depressed patients may access lethal prescriptions. In our study of 58 Oregonians who requested PAD, 18 received lethal prescriptions, including three patients who had met very rigorous criteria for depression. All three died by lethal ingestion within two months of the research interview, though in one case the depression was successfully treated before death and in the other two cases the patients denied that depression was influencing their decision.³⁶ This finding supports the need for more active and systematic screening and surveillance for depression to determine which patients should be referred for mental health evaluation. Despite this finding, the proportion of Oregon and Washington PAD decedents referred for mental health evaluation has remained very low and critics have called for mandatory mental health evaluation in all cases.³⁷ It is unknown how many patients were referred to mental health professionals who found the patient ineligible for a prescription—the health department data of these states only include information on persons who received prescriptions, not those found ineligible. With aforementioned problems with psychiatric evaluation, it remains unclear if mandatory psychiatric assessment would balance the protection of vulnerable persons with advancing patient autonomy, or if it would cast mental health professionals in the role of ethics consultants.³⁸

V CONCLUSION

Oregon now has almost 18 years of experience with legalised PAD. In contrast to concerns that this practice would be common, and be chosen by socioeconomically vulnerable patients unable to access palliative care, studies and reports from the Oregon Public Health Division find that the practice is rare, accessed mostly by educated people with health insurance, most of who are receiving comprehensive end of life care through hospice. A small number of persons with depression do access the law, however, supporting the need for improved screening for mental illness.

³² Ibid.

³³ Ganzini, Goy and Dobscha, above n 26.

³⁴ Hotopf et al, above n 25.

³⁵ Linda Ganzini et al, 'Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide' (2002) 347 *New England Journal of Medicine* 582.

³⁶ Ganzini, Goy and Dobscha, above n 26.

³⁷ Oregon Public Health Division, above n 7.

³⁸ Mark D Sullivan, Linda Ganzini and Stuart J Youngner, 'Should Psychiatrists Serve As Gatekeepers For Physician Assisted Suicide?' (1998) 28 *Hastings Center Report* 14.